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Identifying the Extent of the Cervical Cancer Burden in Indiana

NATIONAL PROGRAM OF CANCER REGISTRIES SUCCESS STORY

SUMMARY: Cervical cancer is almost 100 percent preventable through regular screening, avoidance of controllable risk factors, and vaccination against the human papillomavirus (HPV). Nationally, in 2016 there were 12,984 cases of cervical cancer diagnosed and 4,188 deaths due to cervical cancer. Widespread implementation of Pap testing led to large declines in cervical cancer incidence, but there has been little reduction in cervical cancer rates over the past several years. In Indiana, approximately 262 new cases of cervical cancer and 89 cervical cancer-related deaths occur annually.

The Indiana State Legislature recognized an opportunity to address the state's cervical cancer burden and passed legislation requiring the Indiana State Department of Health (ISDH) to develop a strategic plan to identify and significantly reduce morbidity and mortality from cervical cancer in Indiana.

CHALLENGE: Effective July 1, 2017, the General Assembly of the State of Indiana enacted Section 1. IC 16-46-15 (Chapter 15. Strategic Plan to Reduce Cervical Cancer) to the Indiana Code. Before the law went into effect, the ISDH established an internal workgroup led by the Cancer Control Section, and including partners from the Tobacco Prevention and Cessation Commission; Division of Chronic Disease, Primary Care and Rural Health; Immunization Division; Maternal and Child Health Division; HIV/STD Division; Office of Women's Health; Office of Minority Health; etc., to review current data and related research and publications to determine the best approach for implementing the law.

The workgroup determined early on that a cervical cancer strategic plan of this scope had not been developed by any other states; and, in addition, the extent of cervical cancer burden had not yet been fully examined. The workgroup decided to align the cervical cancer strategic plan with the state cancer control plan and the cancer control continuum. In order to effectively identify the magnitude to which cervical cancer affects women in Indiana, the ISDH examined data from the Indiana State Cancer Registry (ISCR) and other sources for epidemiological analyses to demonstrate the need and support the plan's data-driven goals, objectives, and strategies.

To engage external partners in the development of the Indiana Cervical Cancer Strategic Plan, the ISDH hosted a statewide Cervical Cancer Strategic Planning Kickoff meeting. Over 30 partners from across the state attended the full-day event. Activities included presentations of data, evidence-based practices, and lessons learned related to cervical cancer across the four focus areas of prevention, early detection, treatment, and survivorship. In addition, attendees broke into workgroups based on subject matter expertise, interest, and plan focus areas to draft powerful objectives, which were achievable, had potential for collaboration and impact, and were data-driven.

SOLUTION: The plan serves as a 10-year roadmap for addressing cervical cancer across the cancer control continuum – primary prevention, early detection, treatment, and survivorship. Not only were the ISCR data utilized to provide a comprehensive analysis of the cervical cancer burden in Indiana, but they were also utilized in the formation of SMART objectives.

The cancer epidemiologist analyzed data from the ISCR to determine the extent of the cervical cancer burden in Indiana for the strategic plan. The areas evaluated include incidence and mortality, affected ages, staging at diagnosis, and disparities among race and ethnicity as well as rural and urban populations. In addition, heat maps of Indiana allowed for the visualization of cervical cancer incidence and mortality by county to show geographic areas with relatively higher burdens.

RESULTS: Through the use of cervical cancer data from the ISCR, the ISDH drafted a cervical cancer control plan that demonstrates the cervical cancer burden in Indiana:

The average yearly incidence rate during 2012-2016 was 8.0 per 100,000 women and the mortality rate was 2.5 per 100,000 women. Approximately 43% of cervical cancers were diagnosed among women aged 45 to 64 years from 2012-2016.

The cancer epidemiologist stratified cervical cancer by race and ethnicity to further investigate disparities. African American women in Indiana have statistically higher incidence and mortality rates when compared to White women. The incidence of cervical cancer among African American women from 2002-2016 was 18% higher than the incidence among White women (9.6 versus 8.0 per 100,000 women, respectively). During the same time period, the cervical cancer mortality for African American women was 36% higher than the mortality among White women (3.6 versus 2.5 per 100,000 women, respectively). These findings were crucial for identifying the health care disparities between populations.

The cancer epidemiologist assessed geographic disparities between rural and urban populations, in addition to evaluating overall and racial disparities. From 2002-2016, the incidence rates show that rural counties have statistically higher rates of diagnoses than the urban counties (8.6 versus 8.0 per 100,000 women, respectively). The mortality rates exhibited less of a disparity between the rural and urban counties (2.7 versus 2.5 per 100,000, respectively).

SUSTAINING SUCCESS: The Indiana Cervical Cancer Strategic Plan contains multiple focus areas, goals, and objectives that align with the Indiana Cancer Control Plan 2018-2020 and the cancer control continuum. The plan is set for 10 years, and includes measures of progress to be reviewed in one- and three-year increments. The ISDH will assess progress through multiple data sources, including the Behavioral Risk Factor Surveillance System, National Immunization Survey-Teen, Youth Tobacco Survey, and clinical trials.gov. The ISDH will use data from the ISCR to assess changes in cervical cancer incidence, mortality, racial and ethnic disparities, and rural and urban disparities, and to measure the success of the state's first cervical cancer strategic plan and to guide decision-making for any mid-course corrections in the implementation of the plan.

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